July 24, 2013 MINUTES
PATIENT CHOICE AND MEANINGFUL DISCLOSURE WORKGROUP:
MEANINGFUL DISCLOSURE AT THE HIE WEBSITE SUBGROUP
THE ILLINOIS HEALTH INFORMATION EXCHANGE AUTHORITY

The Illinois Health Information Exchange Authority, pursuant to notice duly given, held a meeting of the Patient Choice and Meaningful Disclosure Workgroup at 10:00 a.m. on July 24, 2013 at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

Particpant Name	Participant Representation
Danny Kopelson	Office of Health Information Technology
Glenn Susz	APP Design
Howard Lee	Wirehead Technology
Victor Boike	MCHC MetroChicago HIE
Sarah Koenig	APP Design
Jodi Sassana	MCHC MetroChicago HIE

- Subgroup Introduction: Subgroup chair, Danny Kopelson, introduced himself to the subgroup and asked the participants in the meeting to do the same.

- Participant Introduction: All present members introduced themselves, the organizations they represented, and their interest in health information exchange. There were no subgroup members participating via telephone.

- Danny Kopelson began the meeting by reviewing the action plan and defining the meeting's objectives: to find the scope and content of meaningful disclosure regarding health information exchange at the level of the HIE website, identify issues of the health information exchange that should be addressed on an HIE website, and develop resources for consumers at the HIE website and for providers at the point of care to ensure that patients receive meaningful disclosure about HIE and their rights with respect to the disclosure of their PHI via an HIE to other providers or third parties.

  o Deliverables: An explanation of the purposes of an HIE, audio, visual, and written instructions of how to opt out of an HIE.

  o Content Required: Each HIE will establish a publically accessible website containing an explanation of the purposes and potential uses of an HIE, audio, visual, and written instructions of how to opt out of an HIE, and the fact that the HIE will disclose patients' health information unless the patient opts out of the process.

  o Form of Disclosure: HIEs may develop additional educational content explaining the opt out policy including signs, posters, brochures, pamphlets, Q and A, etc.

- Danny Kopelson incited discussion by asking whether participants were familiar with the ILHIE website and its information for the consumer.

  o A Participant stated that while the consumer toolkit was informative, it was a bit long for consumers. He suggested that a one page, simple document could be more useful in the education process.

  o Danny Kopelson maintained that although the toolkit is long, it contains necessary information and provides great background information to providers. A successful strategy would draw from the toolkit (perhaps the FAQs section) and insert additional information about the opt out process.

  o Danny Kopelson stated that he would be send participants an email containing other states' information regarding the opt out process. He asserted that a brief, clear document would be the most successful, citing New York's document.

- A Participant recalled a patient focus group session in which participants provided feedback as to what consent information they wanted to know. He wanted to present the results and review them with the group. The Participant also warned against presenting patients with an easy choice to opt. It is beneficial to present the benefits of the HIE and present the choice to opt out afterwards. Depending on where the patient is being presented with the information to opt out makes a difference as well. In the focus group, if a provider gave the patients the information, they did not want to think about it at the time because they were sick and wanted to be treated. Moreover, a three minute informative video was successful since patients were engaged and attentive.

- Danny Kopelson agreed that the three minute video on the ONC's website was very helpful and informative. He recommended that the participants watch it.

- A Participant clarified that in order to meet the criteria for presenting information visually, the medium does not necessarily have to be a video; it could be a PowerPoint, picture, etc.

- Danny Kopelson asserted that the only way patients will find out about the ILHIE website will be through their point of care.

- A Participant asked whether it would be worth considering having a link on provider websites that referred patients to the educational material on the ILHIE website since patients would be more likely to visit their providers' websites instead of ILHIE's.

- A Participant suggested that the ILHIE could make a standardized graphic to be distributed among providers. In this way, the message could be regulated and consistent.

- In conclusion of the meeting all agreed that they would review other state's web pages and provide an outline of their suggestions for the ILHIE website for the next meeting.